



CRS Parent Connection

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CHILDREN'S
Rehabilitation Service

Spring 2003

Meet Our Parent Consultants

Hello, My name is Vivian Spears and I work in the Tuscaloosa office. Although I've lived in Tuscaloosa for several years, I really consider myself a country girl from Choctaw County or rural Alabama.

About seven years ago, I decided to move to Tuscaloosa to get additional services for my son. This was not an easy decision. However, I knew that this was something I had to do. My son Aaron has a diagnosis of Autistic Spectrum Disorder, which has caused a sensory integration dysfunction, speech-language disorder, including stuttering, and visual/auditory perception issues. He most recently was also diagnosed with asthma.

Although we deal with complex issues related to autism, my child's emerging ability to verbally communicate and to reason has been astonishing. I also have a wonderful daughter, Ayeshia. She is 18 years old and currently attends UAB pursuing a degree in nursing. I am very proud of her.



One of the most difficult challenges for my family has been to properly balance our lives. It has been a very complex and sometimes painful learning experience. I can remember my daughter saying to me that, "our life was fine until we had him." I did not know the impact of that statement over 9 years ago. However, the years of coping with the challenge of raising a child with special needs gave new meaning to my daughter's statement. We have been very fortunate to look at the challenges, realize the mistakes, and restructure our lives so that we appreciate and nurture each moment we are together. Ten years later, my daughter and I have begun to work on establishing our mother/daughter relationship. My daughter, Aaron and I are now a very "close-knit" family.

As a parent consultant with CRS, I've been given an excellent opportunity to share resource information, share my experience, provide social support, and listen to the concerns of families. I consider myself very fortunate to serve as a parent consultant for CRS.

Anytime you are in the Tuscaloosa area, please come by to see me. You are also welcome to contact me by phone or email.

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CRS Parent Connection

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Parent Connection is a complimentary Newsletter (published by Children's Rehabilitation Service) for families of children with special health care needs. The goal of this newsletter is to increase communication and share information about children with special health care needs and their families. The newsletter reflects a family-centered theme throughout and serves as a forum for family members to share information, thoughts, feelings, concerns, etc. Nothing printed or implied in this publication constitutes an endorsement by the Alabama Department of Rehabilitation Services.

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From The Director's Chair



Greetings, everyone!

I hope this newsletter finds you and your family doing well. I also hope that by now everyone has had time to recover from the rush of the holidays and to return to a regular schedule. The holiday season is one of my favorite times of the year, but it just seems like it always takes me till about February to get "back in the groove." However, you can rest assured that those of us at Children's Rehabilitation Service are "back in the groove" and working hard to improve the services we provide to Alabama's children with special health care needs and their families. So, here's the scoop on a few things that are happening around here!

We are excited to have recently added a new Parent Consultant position in our Jackson office. We are also currently interviewing to fill the vacant Parent Consultant position in our Opelika office. We believe that the Parent Consultant Program provides much-needed support and critical information to families, and we will do all that we can to continue its growth and improvement.

CRS is also beginning the process to develop an *Alabama 2010 Action Plan for Children With Special Health Care Needs*. The purpose of this initiative is to ultimately develop a comprehensive state community-based service system to meet the needs of Alabama's children and youth with special health care needs and their families by the year 2010. This plan will involve many interested groups and individuals – especially parents. Be on the lookout for more information soon about this important initiative.

In a previous newsletter, I mentioned our beautiful new CRS office in Mobile. Currently, we are working hard to make much-needed improvements in our other offices around the state. We want to make certain that the time you and your children spend at CRS is as pleasant and comfortable as possible. We believe you and your children deserve nothing less and – as you can see – WE ARE MAKING PROGRESS!

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- We have renovated the clinic areas in the Selma and Montgomery offices.
- We have moved into new office and clinic areas in Jackson.
- We have expanded and improved the Audiology suite in our Homewood office.
- We have expanded and improved our Talladega office.
- We will soon expand and renovate our Dothan office and clinic areas.
- We are currently looking to provide new office and clinic space in Huntsville and Andalusia.

All of these improvements are good news and long overdue, as many of you are keenly aware. Alabama's current funding crisis is not good news, however, and I am sure that you also are aware of this. The uncertainty of the economy and the current threat of war have us all worried and on edge. However, I want to assure each of you that the Alabama Department of Rehabilitation Services and the Children's Rehabilitation Service take extremely seriously our responsibility to provide quality services to our state's children with special health care needs and their families. We will do all in our power to continue to provide quality services to the children and families we serve.

Until next time ...

Cary Boswell, Assistant Commissioner
Alabama Department of Rehabilitation Services

Please add me to your newsletter mailing list.

Name: _____

Agency: _____

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What Will HIPAA Mean to Me?



In the last HIPAA notice we said that many of the rules regarding the privacy and protection of a clients' health information are not new. In fact, Children's Rehabilitation Service has always had an obligation to protect the confidentiality of client information. In that case, just what differences will CRS clients and families see after April 14, 2003?

One of the first changes that families may become aware of will be the **Privacy Notice**. CRS is developing a Privacy Notice that will show just how the Protected Health Information (PHI) of each client will be used or released. The notice must also spell out the client's rights and how to complain if those rights are violated. These notices will be very similar to notices you are receiving now from your banks, insurance companies and/or credit card companies.

Another change will be in the **CRS Consent Form**. The new form will be more limited in what permission the family is giving. The new Consent Form also carries a statement that a Privacy Notice was given at the time the Consent Form was signed. **Families will begin to receive the new consent form and a copy of a Privacy Notice around the 1st of March.**

IT IS VERY IMPORTANT THAT THE NEW CONSENT FORMS BE SIGNED AND RETURNED TO THE LOCAL CRS OFFICE BY APRIL 14, 2003.

A third change will be in the way CRS requests and sends PHI. After April 14, 2003 a CRS worker will need to have a family sign a separate **Authorization for Use, Disclosure and/or Release of Information** for each doctor, hospital or therapist that CRS either needs to send information to or get information from. The number of these special permission forms a family may be asked to sign will depend on the number of other medical professionals involved in a child's treatment.

As you may have guessed by now, the biggest change for families will be in the numbers of forms they are asked to sign. The benefit is that these extra steps help to provide additional safeguards to their Protected Health Information.

Linda Jennings, Policy Specialist
Children's Rehabilitation Service

Families and Health Care

Families of children with special health care needs and health care professionals working together in a partnership are a vital part of family centered care. In today's complex health care system, communication between these partners is of utmost importance. Improved communication assists families in making informed decisions regarding care and treatment, and assures them of receiving quality care. To help improve communication the Agency for Healthcare Research and Quality (AHRQ) and the American Academy of Pediatrics (AAP) developed the following list of strategies.

Be Involved in Your Child's Health Care

1. The single most important way you can help prevent errors is to be an active member of your child's health care team.

That means taking part in every decision about your child's health care. Research shows that parents who are more involved with their child's care tend to get better results.



Medicines

2. Make sure that all of your child's doctors know about everything your child is taking and his or her weight. This includes prescription and over-the-counter medicines, and dietary supplements such as vitamins and herbs.

At least once a year, bring all of your child's medicines and supplements with you to the doctor. "Brown bagging" your child's medicines can help you and your doctor talk about them and find out if there are any problems. Knowing your child's medication history and weight can help your doctor keep your child's records up to date. This can help your child get better quality care.

3. Make sure your child's doctor knows about any allergies and how your child reacts to medicines.

This can help you avoid getting a medicine that can harm your child.

4. When your child's doctor writes you a prescription, make sure you can read it.

If you can't read the doctor's handwriting, your pharmacist might not be able to either. Ask the doctor to use block letters to print the name of the drug.

5. When you pick up your child's medicine from the pharmacy, ask is this the medicine that my child's doctor prescribed?

A study by the Massachusetts College of Pharmacy and Allied Health Sciences found that 88 percent of medicine errors involved the wrong drug or the wrong dose.

6. Ask for information about your child's medicines in terms you can understand, both when the medicines are prescribed and when you receive them at the hospital or pharmacy.

- What is the name of the medicine?
- What is the medicine for?
- Is the dose of this medicine appropriate for my child based on his or her weight?
- How often is my child supposed to take it, and for how long?
- What side effects are likely? What do I do if they occur?
- Is this medicine safe for my child to take with other medicines or dietary supplements?
- What food, drink, or activities should my child avoid while taking this medicine?
- When should I see any improvement?

7. If you have any questions about the directions on your child's medicine labels, ask.

Medicine labels can be hard to understand. For example, ask if "four doses daily" means taking a dose every 6 hours around the clock or just during regular waking hours.

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8. Ask your pharmacist for the best device to measure your child's liquid medicine. Also, ask questions if you're not sure how to use the device.

Research shows that many people do not understand the right way to measure liquid medicines. For example, many use household teaspoons, which often do not hold a true teaspoon of liquid. Special devices, like marked oral syringes, help people to measure the right dose. Being told how to use the devices helps even more.

9. Ask for written information about the side effects your child's medicine could cause.

If you know what might happen, you will be better prepared if it does or if something unexpected happens instead. That way, you can report the problem right away and get help before it gets worse. A study found that written information about medicines could help people recognize problem side effects. If your child experiences side effects, alert the doctor and pharmacist right away.

Hospital Stays

10. If you have a choice, choose a hospital at which many children have the procedure or surgery your child needs.

Research shows that patients tend to have better results when they are treated in hospitals that have a great deal of experience with their condition. Find out how many of the procedures have been performed at the hospital. While your child is in the hospital, make sure he or she is always wearing an identification bracelet.

11. If your child is in the hospital, ask all health care workers who have direct contact with your child whether they have washed their hands.

Handwashing is an important way to prevent the spread of infections in hospitals. Yet, it is not done regularly or thoroughly enough. A study found that when patients checked whether health care workers washed their hands, the workers

washed their hands more often and used more soap.

12. When your child is being discharged from the hospital, ask his or her doctor to explain the treatment plan you will use at home.

This includes learning about your child's medicines and finding out when he or she can get back to regular activities. Research shows that at discharge time, doctors think people understand more than they really do about what they should or should not do when they return home.

Surgery

13. If your child is having surgery, make sure that you, your child's doctor, and the surgeon all agree and are clear on exactly what will be done.

Doing surgery at the wrong site (for example, operating on the left knee instead of the right) is rare, but even once is too often. The good news is that wrong-site surgery is 100 percent preventable. The American Academy of Orthopedic Surgeons urges its members to sign their initials directly on the site to be operated on before the surgery.



Other Steps You Can Take

14. Speak up if you have questions or concerns.

You have a right to question anyone who is involved with your child's care.

15. Make sure that you know who is in charge of your child's care.

This is especially important if your child has many health problems or is in a hospital.

16. Make sure that all health professionals involved in your child's care have important health information about him or her.

Do not assume that everyone knows everything they need to. Don't be afraid to speak up.

17. Ask a family member or friend to be there with you and to be your advocate. Choose someone who can help get things done and speak up for you if you can't.

18. Ask why each test or procedure is being done.

It is a good idea to find out why a test or treatment is needed and how it can help. Your child could be better off without it.

19. If your child has a test, ask when the results will be available.

If you don't hear from the doctor or the lab, call to ask about the test results.

20. Learn about your child's condition and treatments by asking the doctor and nurse and by using other reliable sources.

Ask your child's doctor if his or her treatment is based on the latest scientific evidence. For example, treatment recommendations based on the latest scientific evidence are available from the National Guideline Clearinghouse™ or other Web sites such as healthfinder® at <http://www.healthfinder.gov/>.

Strategies reprinted from "Patient Fact Sheet", Agency for Healthcare Research and Quality, www.ahrq.gov

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MEDICAID COVERAGE UPDATE

The Alabama Medicaid Agency has added coverage for the following services for a Medicaid approved cochlear implant recipient:

Effective June 1, 2002, coverage was added for a personal FM receiver and its compatible transmitter microphone. This service is covered upon request and after prior authorization. The replacement of lost or damaged external components (when not covered under the manufacturer's warranty) will be a covered service when prior authorized by Medicaid (cords, etc).

Effective January 1, 2003, coverage was also added for a cochlear implant external processor. This service is also covered upon request and after prior authorization. In addition, accessory replacement (processor battery, cords, etc) was also added for coverage, but as with the other services, replacement requires prior authorization by Medicaid.

These services must be requested by your hearing provider. If they need additional information please have them call Medicaid's Clinic/Ancillary Program at 334-242-5455.



National Conference

Representatives from almost every state (including Alabama) met in Washington DC, February 6-9, for Family Voices' 10th Annual National Conference and Anniversary Celebration. This year's conference, "From Participants to Partners," honored the great strides parents/families have made in the past ten years affecting policy and system changes for their children and youth with special health care needs. The conference featured workshops to help family leaders face current challenges, including Title V Block Grant training, "Family Roles in Program and Policy," National Disability Mentoring Day, State Children's Health Insurance Program, and Leadership in Family-Led Organizations, among other topics. Three of the many guest speakers included Dennis Smith, director of Medicaid, CMS; Bob Pasternak, assistant secretary, OSERS; and Polly Arango, former executive director of Family Voices.

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New Brochures Available from Family Voices

Family Voices is pleased to announce five brochures which have been developed for families of children with special health care needs and professionals implementing family centered care. The titles are *Health Insurance Laws at Work and Related Rights*, *Working with Caregivers in Your Home*, *Meeting Your Child's Health Care and Related Needs at School*, *Planning for Medical Emergencies* and *Working with Families as Partners and Consultants*. If you are interested in one or more of these topics, these brochures are available by email in PDF format or they can be mailed to you. Contact us through the phone numbers or website listed below.

Congratulations to Nick Dupree!!

You may remember Nick Dupree, a college student from Mobile who was due to lose his much-needed home nursing services provided by Medicaid when he turned 21 on February 23, 2003. Nick mounted a campaign called "Nick's Crusade" to try to change the system so that he could remain at home with his family and not be sent to live in a nursing home in Louisiana.

On Tuesday, February 10, Health and Human Services Secretary Tommy Thompson announced the approval of the Alabama Medicaid Agency's request for a new Medicaid waiver in Alabama that will assure continued support for people who might otherwise lose their services simply because they turn twenty-one. He said, "The Bush administration is committed to helping states and the disability community change old programs and develop new ones that will serve people with disabilities in the settings that work best for them." The President has strongly encouraged states to develop better community services through his New Freedom Initiative which directs federal agencies to tear down barriers that prevent community living for people of any age who have a disability. The new waiver will cover 30 people in Alabama.

Nick has been a part of Family Voices of Alabama's Family to Family Health Information Council, and after learning of the decision he said, "I plan to keep working on this the rest of my life to make sure that everyone can be safe and live in their community and not be locked away in a faraway nursing home."

For more information visit Family Voices on the web at www.familyvoices.org or contact Family Voices of Alabama coordinators Jerry Oveson (251-438-1609 or oveson@bellsouth.net) and Susan Colburn (1-800-846-3697 or scolburn@rehab.state.al.us).

Making the Transition from Youth to Adult Medical Care

By Merle McPherson, MD, director
Gloria Weissman, deputy director
Division of Services for Children
With Special Health Needs
(Maternal and Child Health
Bureau)(Health Resources and
Services Administration)

The President's New Freedom Initiative calls for removing barriers that prevent people with disabilities from living in their communities. In the New Freedom Initiative report, *Delivering on the Promise* (dated March 25, 2002), the Health Resources and Services Administration (HRSA), is acknowledged as the federal agency with program responsibility for addressing the barriers to children and youth with special health care needs.

HRSA is charged with developing a plan aimed at eliminating those barriers. The report identifies the following target areas: comprehensive, family-centered care, affordable insurance, early and continuous screening for special health care needs and transition services to adulthood.



The report also notes the following issues for families of children with special health care needs: (1) need for family satisfaction, and (2) complexity and organization of services resulting from fragmentation and multiple funding streams.

As states look at the health and welfare of its citizens and build community systems of care, youth with special health care needs should be considered carefully. The fact that more children with special health care needs are living to adulthood is wonderful and remarkable. Improved medical science, technology and outstanding care may allow many to progress with their adult lives barely impacted. For others, however, adulthood may present challenges to attaining the milestones that

most take for granted – education, employment and independence.

Medical Insurance

According to the Social Security Administration, there are nearly one million children under age 18 receiving Supplemental Security Income (SSI) payments based on disability. Another 500,000 adult recipients first became eligible as children.

Many more enter the SSI system as “adults” at age 18, when parents’ income and resources are no longer considered, even though their medical condition would have qualified them at an earlier age.

The actuarial projections are that a recipient who first starts receiving SSI as a child will collect payments for almost 30 years. This represents a significant dependence on federal and state funds. Even those who are able to graduate from high school and college are often unable to make the transition to employment and leave the SSI rolls. While there are probably a number of reasons for this, access to and utilization of health care seem to figure prominently.

The older the children are, the less likely it is they will have health insurance. For those receiving SSI and Medicaid, many lose that coverage at adulthood. For those who continue, however, once they age out of the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program, covered items and services drop significantly.

On the private insurance side, coverage under the plan of a parent usually has an age limit. While the age limit may or may not be extended if the youth has special health care needs, often the plan is either too expensive or inadequate to cover all of the youth’s needs.

If a youth is working, part-time and entry-level service jobs do not provide health insurance coverage. All of this adds up to the potential decreased access to and utilization of health care

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at the time the youth is making the transition to adulthood.

From Child to Adult Medical Care

The actual transition from pediatric to adult medical care can be a difficult process for youth with special health care needs. Many youth and parents express strong ties to devoted pediatricians who have provided treatment for long periods of time, if not entire lifetimes. Thoughts of changing providers can be frightening, especially if the idea is unexpected. Furthermore, many pediatricians are reluctant to turn over care of a patient with special health care needs to another provider who may not be as familiar with the specific condition or need. On the other hand, many individuals say that their pediatric providers have not addressed adult issues. They report feeling embarrassed and demeaned as young adults who are in their 20s or even 30s, and are still seen in pediatric offices, clinics, and hospitals. Pediatric-trained providers can sometimes miss signs and symptoms that would be recognized by adult-focused providers.

The transition to adult care would seem to be most effective and most easily achieved if it was anticipated and planned for from the earliest point in the child's treatment. So that youth and families do not feel forced to change providers or do not feel trepidation over the quality of care to be received in the future, the transition should be expected, well thought out, and managed to minimize any negative impact. It should be one more informed choice made by the patient, family and health care provider. That is the course taken in the HRSA's National Health and Ready to Work (HRTW) initiative.

HRTW Projects

The six state implementation grant projects (Arizona, Iowa, Kentucky, Maine, Mississippi and Wisconsin) currently running in Phase II of the HRTW initiative are all looking at the issues involved with transition from pediatric to adult health care.

The Kentucky TEACH project has changed the way the Kentucky Commission for Children with Special Health Care Needs interacts with children



and families. Through the use of "Life Maps" and introduction of a computerized tracking system, the Kentucky commission now focuses on transition at every point of contact with the child and family.

The Life Maps are designed to both elicit information about the child's status and progress and to give age-appropriate advice for ways the family can help prepare the child for future transition. Information is put into a database and it is then available for future contact with the child and family. This gives the commission staff a focused way to track the child's progress, identify specific family needs, and match with or refer to available resources. It also provides management information data for this population of children and youth.

This change in focus at the commission was achieved in part by changing the job descriptions and performance plans of staff to reflect transition as a required element. That signaled to the staff the importance and value of transition as part of the services provided by the commission to the citizens of Kentucky.

Using the Medical Home

In addition to the issues that youth, families and pediatric providers face, finding adult providers who are willing and able to accept youth with special health care needs into their care can be a challenge in certain parts of the country. A number of the HRTW projects are approaching this issue as a part of the medical home concept.

The thinking is that comprehensive and coordinated care in the medical home would include planning for a transition to an appropriate adult provider. The grant project in Arizona, for example, has recruited adult providers who work with the

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various health plans and are willing to accept youth with special health care needs as patients. Linking those providers with the medical home will hopefully ease the entire transition process. It is already clear that a training need exists and the HRTW initiative will be focusing on how to address that need with the adult provider community.

Also the HRTW initiative and the state implementation grant projects are looking at ways to address the insurance issue. In general, lack of information is a major factor. It seems that many youth and families would benefit from the assistance of a transition coordinator or facilitator who would help them explore the various options and find access to needed care, services and insurance.

Cultural Issues

Furthermore, there are cultural competency issues that impact access to and utilization of health care. Some minority populations are historically underserved as stated above. The situation worsens as these youth move into adulthood. Some cultures have different values about health and health care that may impact issues, such as if, or when, treatment is sought, whether or not medications or invasive procedures will be used, and at what age youth will begin to exercise control over medical decisions. When providers are culturally competent, care improves and families express increased satisfaction. The HRTW National Center is working with the National Center on Cultural Competency to further identify and address the needs of minority youth in transition.

By providing youth and families with as much information as possible and building a system of care that encompasses the medical home concept, including planning for and facilitating the transition to adult health care, the HRTW initiative aims to enable youth and families in making choices that allow for a full, rewarding and independent life in their community.

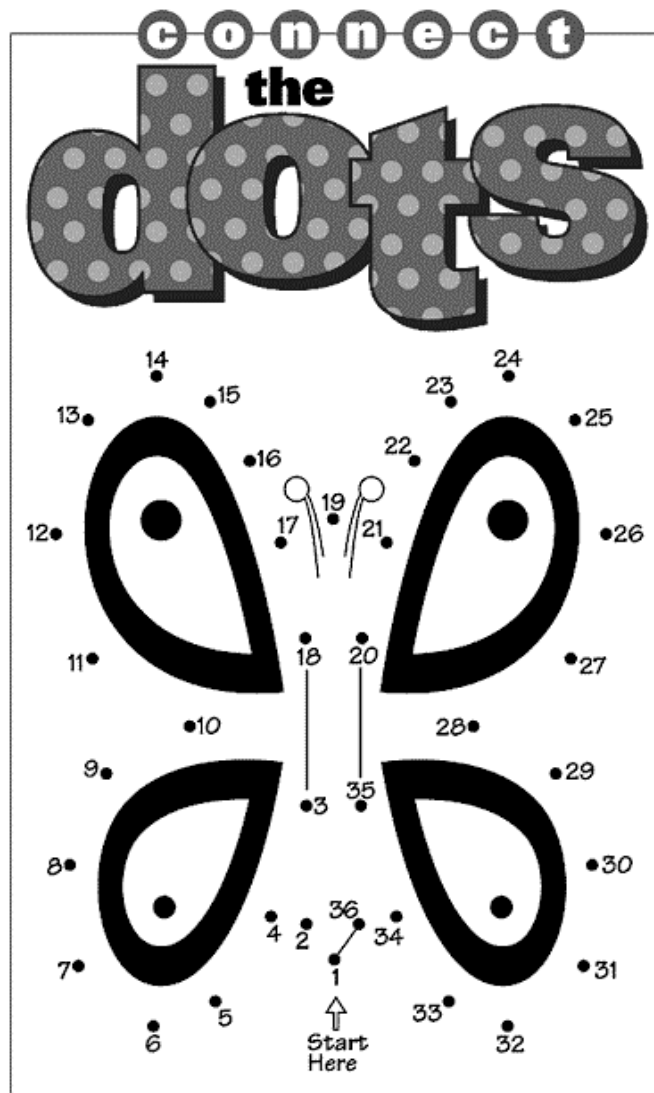
Tips for Parents

Rearing children of character demands time and attention. While having children may be “doing what comes naturally,” being a good parent is much more complicated. Here are five tips to help your children build strong character:

- 1. Be a good example.** Face it: human beings learn primarily through modeling. In fact, you can’t avoid being an example to your children, whether good or bad. Being a good example, then, is probably your most important job.
- 2. Develop an ear and an eye for what your children are absorbing.** Books, songs, TV, the internet and films are continually delivering messages—moral and immoral—to our children. As parents we must control the flow of ideas and images that are influencing our children.
- 3. Get deeply involved in your child’s school life.** Helping our children become good students is another way of helping them acquire the habits they build strong character.
- 4. Make a big deal out of the family meal.** Manners, rules and values are subtly absorbed over the dinner table. Family mealtime should communicate and sustain ideals that children will draw on throughout their lives.
- 5. Do not reduce character education to words alone.** We gain virtue through practice. Parents should help children by promoting moral action through self-discipline, good work habits, kind and considerate behavior to others and community service. The bottom line in character development is behavior—their behavior and yours.

Source: Kevin Ryan’s “Ten Commandments for Parents,” Appendix I in “Building Character in Schools” (Ryan, K. and Bohlin, K.E.; Jossey-Bass, 1999)

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Camp ASCCA Summer 2003

It's already time to plan for summer camp! CRS will sponsor a limited number of camperships available through each district office. In order to apply for a CRS campership, a child must be enrolled in the CRS program and be at least 6 years old, but no older than the age of 20 by the date of summer camp. CRS will then submit the applications to Camp ASCCA, who makes all final decisions regarding acceptance to the various camps.

If you are interested in more information about the Camp ASCCA Summer Camp 2003 CRS camperships, please contact your care coordinator at your local CRS office. And please remember that these camperships are limited, so don't delay!



Kim McLaughlin
CRS State Hemophilia Coordinator



CRS Parent Connection

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JOIN PARENT TO PARENT TODAY!!! All you have to do is fill out a form about your family and your child with special needs. You are then matched with a parent who is in a similar situation. You and your "match" can then talk on the phone and/or meet in person to provide support and information. See your parent consultant to complete a form.



Out What's Ahead

- | | |
|--------------------|---|
| March 6-7, 2003 | ASD Making a Difference Conference, Adam's Mark Hotel & Resort, Mobile, AL; Contact: www.asdconferences.com , 1-877-782-7347, email: info@asdconferences.com |
| May 15-16, 2003 | ACDD Annual Meeting - open for public comments; Contact: 1-800-232-2158 |
| June 4-7, 2003 | National Council on Independent Living Conference, Washington D.C.; Contact: 1-800-833-1354, www.ncil.org |
| June 11 - 13, 2003 | 5th Annual Supported Employment Conference, Adam's Mark Hotel, Mobile, AL; Contact: Byron White, ADRS 1-800-441-7607 or Lisa Alford (205)554-1300 |
| June 18, 2003 | Alabama Disabilities Action Coalition Meeting, Tuscaloosa, AL; Contact: www.accessalabama.org |
| June 19 - 23, 2003 | RESNA 26th International Conference on Technology & Disability, Hyatt Regency, Atlanta, GA; Contact: RESNA (703)-524-6686, email: info@resna.org , www.resna.org |